

Introduction

Idiopathic intracranial hypertension (IIH) is a rare disabling condition characterised by elevated intracranial pressure (ICP) and people with IIH (pwIIH) experience chronic headaches alongside other symptoms such as visual loss (1). Although the mechanisms are not fully understood, weight loss is currently the main disease modifying therapy recommended, with a weight loss of approximately 15% of total body weight often being sufficient to induce remission (2). Establishing the most effective means of weight loss in the short and long term has been highlighted as one of the top 10 priorities for research by patients, clinicians and carers (Figure 1) (3).

Physical activity is a cornerstone of weight loss management programmes. Global guidelines also suggest that adults with chronic conditions or disabilities should accumulate over 150 minutes of moderate to vigorous intensity physical activity over the course of a week (Figure 2) (4). Physical activity levels are not yet known for pwIIH but are reported to be lower in people with obesity, migraine and co-existing headache conditions compared to the general population (5). Exercise is one element of physical activity (Figure 3). IIH has also been shown to negatively affect Health Related Quality of Life (HRQoL) (6). There is accumulating evidence of a positive association between exercise and HRQoL in the general adult population (4), and people with chronic headache conditions such as migraine (7)]. However, this relationship has not been explored in pwIIH.

Both physical activity and exercise are potentially modifiable behaviours that as well as playing a role in weight loss, may also improve HRQoL and reduce the risk of secondary diseases.

Question –How active are pwIIH and are there associations between physical activity, quality of life and headache in pwIIH



Figure 1

James Lind Alliance Research Priority Setting Partnership in IIH (3)

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Associations between physical activity, quality of life and headache in people with Idiopathic Intracranial Hypertension

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Methods

An online questionnaire distributed by IIH UK.

The questionnaire included:

- Background demographics and clinical characteristics (current and diagnosis weight, height, gender, living arrangements ethnicity and self-reported presence of papilloedema).
- A measure of health-related quality of life; the SF-36®. Scores from individual sections are used to calculate physical (PCS) and mental component scores (MCS). Scores range from 0-100, with higher scores indicating better health related quality of life.
- A measure of physical activity -the Physical Activity Scale for Individuals with Physical Disabilities (PASIPD) a standardised, 13 item self-report questionnaire. Time spent participating in leisure, household and occupational activities over the past 7 days is recorded (Figure 3). An overall physical activity score is calculated with scores range from 0.0 MET hr/day (not performing activities) to 199.5 MET hr/day performing all the activities for the maximum amount (days and hours).
- The Headache Impact Test (HIT-6™) was used to quantify the impact of headache in pwIIH. The HIT-6™ is a 6 item selfscored test with scores ranging from 36 -78 with higher scores indicate greater headache impact.



Figure 2 WHO physical activity guidelines for adults with Chronic disabilities (4)

Results

- 164 pwIIH completed the questionnaire. Participants were predominantly female (97%) with an increased BMI>35 (83%). HRQoL was low (PCS and MCS) and headache impact scores high commensurate with previous reports (Table 1).
- PASIPD measures showed that participants had low levels of physical activity similar to those of people with stroke and other physical disabilities.
- Participants also had a low level of engagement with exercise (75%, 89% and 95% reported never engaging in light, moderate or strenuous exercise respectively) and muscle strengthening programmes (82% reported never engaging in exercises to increase muscle strength or endurance). (Table 2)
- Significant moderate correlations were found between PASIPD total score, headache impact, and health related quality of life (PCS, physical functioning, physical role, general health, vitality and social role) (Table 3).
- Physical activity was not related to MCS, age, current or diagnosis BMI (Table 3)



Characteristic	Median (Inter-	Range				
Headache Disability HIT-6™	quartile range) 66 (7)	36-78				
Physical Activity (MET						
hrs/day)						
PASIPD total	10.38 (17.6)	0-57.3				
Component scores						
Sport, exercise and	3.22 (5.63)	0-24.5				
leisure						
Household activity	3.92 (7.04)	0-24.13				
Occupational activity	0 (11.25)	0-19.28				
HRQoL SF-36®						
Physical Functioning	44 (24)	12-88				
Physical Role	36.17 (18.88)	15.19-57.14				
Bodily Pain	27.95 (7.08)	27.95-56.24				
General Health	46.48 (9.42)	19.93-62.75				
Vitality	34.5 (7.95)	21.86-54.63				
Social Role	37.22 (9)	26-54				
Emotional Role	35.42 (0)	25-52				
Mental Health	24 (32)	24-55				
Physical Component	32.27 (14)	14-57				
Score (PCS)						
Mental Component	40.31 (7)	26-54				
Score (MCS)						
		ed 36-78 with higher s res indicating				

greater headache impact, PASIPD, physical activity scale for people with physical disabilities scored in MET hr/day (0-199.5) total, , HRQoL Health related quality of life measured by SF-36® Short Form 36 items component scores Physical Component Score (PCS) and Mental Component Score (MCS) and scores for each subsection range from 0-100 with scores of 50 representing the average score for the population.

Table 1 Outcome Measures

Question	Subject	How often	(days)?		How many hours per day?				
		Never	Seldom (1- 2 days)	Sometimes (3-4 days)	Often (5-7 days)	<1hour	1-2 hours	2-4 hours	>4 hours
	Leisure time activities								
1	Stationary activities	3 (2)	16 (26)	28 (46)	54 (89)	9 (15)	21 (33)	45 (72)	25 (40)
2*	Walk outside your home	7 (11)	25 (41)	31 (51)	37 (61)	35 (53)	34 (52)	16 (25)	15 (23)
3	Light sport or recreational activities	75 (123)	17 (28)	6 (3)	2 (2)	43 (17)	37 (15)	15 (6)	5 (2)
4*	Moderate sport or recreational activities	95 (155)	4 (6)	2 (3)	0	45 (4)	45 (9)	10 (1)	0
5	Strenuous sport and recreational activities	89 (146)	8 (13)	2 (3)	1(2)	50 (9)	39 (7)	11 (1)	0
6	Exercise to increase muscle strength and endurance	82 (134)	12 (20)	3 (5)	3 (5)	73 (22)	27 (n=8)	0	0
	Household activity								
7	Light housework	9 (13)	28 (47)	29 (48)	34 (56)	49 (69)	39 (59)	15 (22)	1 (1)
8	Heavy housework	34 (56)	48 (79)	12 (19)	6 (10)	61 (66)	32 (35)	9 (6)	1(1)
9	Home repairs	97 (195)	3 (5)	0	0	80 (4)	20 (1)	0	0
10	Lawn Work	88 (144)	12 (20)	0	0	45 (9)	35 (7)	15 (3)	5 (1)
11	Outdoor gardening	84 (138)	13 (22)	3 (4)	0	46 (12)	56 (14)	0	0
12	Care for another person	36 (59)	14 (23)	5 (9)	45 (73)	9 (9)	13 (14)	12 (13)	66 (69)
	Work-related activity					<1 hour	1-4 hours	5-8 hours	>8 hours
13	Work for pay or as a volunteer	56 (92)	9 (15)	10 (17)	25 (40)	6 (4)	14 (10)	38 (27)	43 (31)

Table 2 PASIPD Detail

	Age	Current BMI	HIT-6™	SF36® Physical Functioning	SF36® Physical Role	SF36® Bodily Pain	SF36® General Health	SF36® Vitality	SF36® Social Role	SF36® Emotional Role	SF36® Mental Health	SF36® Physical Component Score	SF36 [®] Mental Component Score
PASIPD total	score												
Correlation Coefficient	0.049	-0.055	-0.338**	0.422**	0.376**	0.119	-0.402**	0.196*	0.372**	-0.081	0.083	0.422**	0.072
Sig. (2- tailed)	0.535	0.483	<0.001	<0.001	<0.001	0.128	<0.001	0.012	<0.001	0.302	0.29	<0.001	0.362
PASIPID leisu	re time												
Correlation Coefficient	-0.017	-0.146	-0.211**	0.391**	0.404**	0.015	-0.346**	0.107	0.337**	-0.037	0.072	0.391**	0.073
Sig. (2- tailed)	0.833	0.061	0.007	<0.001	<0.001	0.85	<0.001	0.171	<0.001	0.638	0.362	<0.001	0.352
PASIPID Hous	sehold												
Correlation Coefficient	0.074	0.04	-0.175*	0.286**	0.195*	-0.006	-0.185*	0.204**	0.226**	-0.031	-0.007	0.286**	0.029
Sig. (2- tailed)	0.348	0.613	0.025	<0.001	0.012	0.934	0.018	0.009	0.004	0.694	0.925	<0.001	0.713
PASIPID Wor	k related												
Correlation Coefficient	0.06	-0.026	-0.288**	0.280**	0.235**	0.180*	-0.331**	0.196*	0.216**	-0.044	0.02	0.280**	0.096
Sig. (2- tailed)	0.444	0.745	<0.001	<0.001	0.002	0.021	<0.001	0.012	0.006	0.573	0.795	<0.001	0.219

Table 3 Physical Activity Associations

Conclusions

This survey shows that pwIIH have low levels of physical activity in all areas measured: sport, exercise and leisure activities, household and work-related activity similar to people with physical disabilities.

Physical activity had a significant moderate positive relationship with headache impact and physical dimensions of quality of life as measured by the SF-36.

These results suggest that supporting people to engage in physical activity could have beneficial effects. Future research should explore barriers and enablers of exercise/ physical activity in pwIIH and methods of increasing physical activity.

Physical Activity Leisure Work (includin Household exercise

Figure 3 Physical Activity Components